

**\*\*EMBARGOED UNTIL WEDNESDAY, MAY 10, 2017, AT 2:30p.m.\*\***

Cyndi Johnson

Written Statement Prepared for DPCC Hearing

May 10, 2017

Honorable members of Congress, it is my great honor to be with you this afternoon. Allow me to express my deep gratitude to Senator Stabenow and the Democratic Policy and Communications Committee for inviting me to share my family's story today. Let me first say that nearly 27 years ago to the day, along with my high school senior class, I proudly posed for a photograph on the steps of the Capitol Building with Senator Richard Lugar and Congressman Lee Hamilton. And I have fervently followed congressional activities ever since. To testify before you today and potentially impact millions of Americans with special health care needs who can't afford to lose their health insurance is truly an opportunity beyond my wildest dreams.

You see, I come from a background of generational poverty in the hills of southern Indiana. My grandfather eked out a living for his family of seven by farming a small patch of land overlooking the Ohio River. My other grandfather was an orphaned German immigrant with no formal schooling who supported a family of 7 by working at a grocery store. My parents were also among the working poor—a construction worker and a secretary—but we still relied on food stamps and free school lunch to make ends meet. We couldn't afford health insurance, so it was lucky that we were generally healthy apart from the occasional cold. Throughout my own schooling, I worked diligently and was awarded numerous college scholarships, becoming the first person on either side of the family to earn a degree. I went on to work as a math teacher in Indiana for years and even earned a master's degree. But later, when I started a family of my own and discovered prenatally that I was going to have a baby girl with Down syndrome, my life changed dramatically.

It became clear shortly after she was born that to coordinate her medical care, I would need to become a stay-at-home mom. Virtually overnight, we went from being a two-income family with no medical expenses to a one-income family with astronomical medical expenses. I remember standing at the mailbox with my tiny baby—she was still under 10 pounds at 11 months old—cradled in my arms and opening an envelope from the children's hospital with a bill inside for \$64,000--more than my husband's annual salary--for merely "renting" the surgical room and equipment used during her heart surgery the month before. I fought back tears as I tried to wrap my mind around it--recognizing that more bills would soon arrive in my mailbox for the hospital stay, surgeon's fees, and more. Then it hit me: This was our new reality. And I honestly felt as if my hard-earned middle class lifestyle was slipping away.

Over the next several years, even with private insurance through my husband's employer, the bills added up quickly. Besides deductibles and copays, there were many expenses insurance didn't cover: medical equipment and supplies, high-tier medications, out-of-network specialists, therapies, incontinence supplies, specialized feeding supplies, travel, and more. Medical testing led to more medical testing, but with few answers and solutions. Even Mayo Clinic declined her case, citing that they could only duplicate tests we had already tried. Our out-of-pocket costs were spiraling with no end in sight, yet my daughter's condition deteriorated. We even took out a home equity line of credit, and all the while the cost of my precious daughter's care was fast approaching the lifetime cap on medical expenses imposed by our private insurance.

Then came the Affordable Care Act in 2010--covering 28 million Americans who were previously without health insurance. My family was so grateful, not only for all those Americans gaining the peace of mind of having health coverage, but for the peace of mind we had knowing that lifetime caps had been eliminated. Without this provision, my daughter would easily have exceeded her lifetime cap by age five.

Of course, there was still the issue of our mounting medical debt. But then in 2015 after being on a waiting list since birth, my then-8-year-old daughter became eligible for the Medicaid waiver in the state of Indiana, making her eligible for Medicaid Disability. Medicaid now covers much of what private insurance does not, and while the system is still far from perfect, it has meant a much brighter financial future for my family. I am pleased to report that I have re-entered the workforce, and my family has made progress toward paying down medical debt and saving for college for my other two children.

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I hear many members of Congress emphatically stating that the Affordable Care Act is a disaster, but presenting little to no factual evidence to support that claim. Americans want to get and keep their health insurance. This is evidenced both by the high number of people rushing to enroll in a Marketplace plan during the last enrollment period and by the nationwide intense opposition to the American Health Care Act that was pushed through last week in the House, even before it could be scored by the Congressional Budget Office. So here's what I do know: Not having health coverage or limiting access through costly high-risk pools and expensive premiums will spell actual disaster for millions of Americans—up to 24 million people—especially among the most vulnerable populations: those with pre-existing conditions, seniors, individuals with disabilities, low-income households, pregnant women, and more.

In fact, not having access to quality medical care would be a disaster for families across the country that I personally know and love, and whose stories I share now with their consent. For my son's fifth-grade classmate, Bella, who has epilepsy and who also happens to live in the same neighborhood as Senator Todd Young. For my former colleague in California whose daughter Vivian requires a tracheotomy to breathe due to the tumors in her throat that keep growing back. For my friend in Indiana whose quadruplet sons—two of whom are on the autism spectrum and one of whom has cerebral palsy—have successfully secured community employment and are able to live more independently in their community with support services provided by the Medicaid waiver. For a friend in Louisiana I only know through Facebook because of the common health care struggles we face whose 13-month-old son Carter has Global Developmental Delay and multiple severe medical conditions due to a rare disease he contracted at just 3 months of age. For my dear friend right here in the Washington D.C. area whose 11-year-old daughter, Eliza, was born blind and has cerebral palsy and microcephaly. And for my own precious daughter with Down syndrome, who I am very pleased to report had a successful procedure in August at Nationwide Children's Hospital in Columbus, Ohio that has been complete game-changer in her day-to-day health, and for the first time ever, she is attending school full time as a happy second grader and Brownie Scout, and speaks with pure joy radiating from her smiling face when she talks about the friends she has made there.

As a parent, absolutely nothing else matters when your child is sick. Your world shrinks and everything else just falls away. I would have sold my house, my car, done literally anything to keep my daughter healthy -- and no family should have to make that horrible choice. No parents should have to worry that providing life-saving care to their children might send them into bankruptcy. The Affordable Care Act, and the accompanying changes to Medicaid, quite literally meant the difference between life and death for my daughter, and have given my family a chance to live the financially secure life we've worked so hard to achieve.

Senators, I urge you to do whatever is necessary to ensure that the critical provisions of the ACA are maintained, and that you reject any legislation that seeks to move Medicaid to a block grant or per capita funding model, as that would limit vital services for persons with disabilities and low-income households. I urge you to preserve essential benefits like hospital coverage, emergency room visits, prenatal and maternity care, mental health services, and substance abuse treatment. Protecting these key benefits helps ensure better health and financial security for all. Access to health coverage is a lifesaver for Americans, and the repeal of the ACA would be devastating to tens of millions of families. We must do everything we can to keep health insurance accessible, affordable, and comprehensive. The stakes are just too high. Thank you, Senators, for your time and consideration.